Ethics Corner: Cases from the Hebrew Rehabilitation Center for Aged—Truth or Consequences

Eran D. Metzger, MD, and Muriel R. Gillick, MD

This article is the fifth of a six-part JAMDA series devoted to medical ethics in the nursing home. In each issue, a case is presented from the Ethics Committee at the Hebrew Rehabilitation Center for Aged (HRCA) in Boston, Massachusetts. Following a description of the case and a discussion of the ethical issues that the case raises, Dr. Steven Levenson will discuss the implications for medical directors.

TRUTH OR CONSEQUENCES

The good, which may be done by deception in a few cases, is almost as nothing, compared with the evil which it does in many, when the prospect of its doing good was just as promising as it was in those in which it succeeded. And when we add to this the evil which would result from a general adoption of a system of deception, the importance of a strict adherence to the truth in our intercourse with the sick, even on the ground of expediency, becomes incalculably great. –Worthington Hooker, 1849

CASE PRESENTATION

Charlotte R. is a 91-year-old woman who was admitted to the Hebrew Rehabilitation Center for Aged (HRCA) 2 years ago when, because of moderate dementia, she could no longer live independently. Mrs. R. was born and raised in New York and moved to Boston after she married. She raised a daughter, who eventually moved to the West Coast. Mrs. R. became widowed when she was 75. Several years before her admission to HRCA, she designated a niece who lived in Boston as her health care proxy. Mrs. R. made a smooth transition to HRCA. At the time of the ethics consult, she had developed a close relationship with a gentleman resident at the center and had not inquired about her daughter in approximately 9 months.

Mrs. R.’s treatment team (nurse, physician, and social worker) consulted the Ethics Committee after learning from the niece that Mrs. R.’s daughter had died and that the niece did not want this information to be shared with Mrs. R. Mrs. R.’s niece explained to the team that she was fearful the news would cause her aunt unnecessary distress. Mrs. R.’s primary caregivers recognized that their responsibility for truth telling pertained primarily to medical information, and they were prepared to honor the niece’s request to keep secret this personal information. Nevertheless, they questioned whether such nondisclosure was ethical. The caregiving team expressed their willingness to break the news themselves to Mrs. R. if the niece wished.

The Ethics Committee consultants reviewed the potential consequences of disclosure and nondisclosure. The consultants noted that disclosure would likely cause Mrs. R. sadness but that there was no evidence she had been unable to engage in healthy grieving in the past. The consultants informed the team that, with regard to medical diagnoses, the medical literature indicated that fears about patient decompensation after truth telling were exaggerated. On the other hand, failure to disclose the information could cause Mrs. R. to lose trust in her family and caregivers were she to learn the truth inadvertently. The consultants observed that nondisclosure put the staff in an awkward position and denied Mrs. R. the opportunity to mourn a loss.

The consultants recommended to the team members that they explain to the niece their willingness to respect her decision but that her fears about disclosure were not likely to be realized. The consultants recommended informing the niece of the caregiving team’s expertise and sensitivity in assisting residents with grieving.

The caregiving team members subsequently met several times with Mrs. R.’s niece. The niece gradually accepted the team’s position that caregivers would not lie if Mrs. R. asked about her daughter. Three months after the Ethics Committee consultation, Mrs. R. did inquire of a nursing staff member about her daughter. She accepted the news without incident and with little emotion.
CASE DISCUSSION

The case of Mrs. R. represents one of many possible scenarios in which a healthcare professional may be urged by family to withhold information from a nursing home resident. For various reasons, family members believe that disclosure will cause harm to the resident, putting the provider in the position of choosing between dishonesty and maleficence. In more extreme and yet not uncommon cases, a provider may be requested by family members to conceal a diagnosis or treatment options from a competent resident. The pressure brought to bear on the provider can be significant, with threats made to transfer the resident to another facility or to sue.

Beauchamp and Childress have offered three arguments why veracity is fundamental to the clinician/patient relationship. They argue first that respect for autonomy requires full disclosure if consent is to be truly informed and valid. Second, they maintain that in the clinician-patient relationship there is an implicit contract wherein both the patient and the clinician have a right to truthful disclosure from each other. They see this as an extension of a social contract in which, when one speaks, one implicitly promises to speak truthfully and not deceive one’s listener. Finally, successful doctor-patient relationships depend on trust, and veracity is essential to ensuring this trust.2

In Mrs. R.’s case, there was no history that she had reacted pathologically to loss in the past. The caregiving team believed that the proxy was trying to protect Mrs. R. from discomfort but did not agree that such discomfort rose to the level of harm. The team was also suspicious that the niece, perhaps unconsciously, was acting to spare herself the discomfort involved in conveying the sad news to her aunt. The team members’ concerns can be understood in part as resulting from the nature of the relationship they had with Mrs. R. Had Mrs. R.’s daughter died while Mrs. R. was receiving treatment in the acute care hospital, it is unlikely that the hospital team would have felt compelled to challenge the niece’s decision. Indeed, it is unlikely they would have even learned about it. The relationship between caregiver and resident in the nursing home is quite different, however. By virtue of daily contact, nursing home clinicians often develop strong bonds to “their” residents. In this setting, clinicians have spoken of the difficulty relating to a resident on a day-to-day basis while having to withhold important information.

Recent studies of patients’ attitudes toward the dying process have increased caregiver sensitivity about the importance of disclosure. Studies of patients in the United States with terminal illnesses such as cancer and AIDS have generally shown that patients want to be informed of prognosis and feel they need this information in order to plan for a good death.3,4 Interestingly, however, in a small study of geriatric outpatients, not having knowledge of impending death was endorsed as an attribute of a good death more often than having this knowledge.5 A comprehensive review of the literature on patient autonomy reveals that while many patients prefer that others make decisions for them, the vast majority wish to know about their situation.6

The team’s concerns can also be understood as a result of relatively recent developments in ethics in the health professions. Correlating with the rise of biomedical ethics and the doctrine of informed consent, physician practice in the area of truth telling has changed substantially over time. A study on telling cancer patients their diagnosis, first done in 1961, indicated that 90% of physicians did not reveal the diagnosis.7 When the study was repeated in 1977, 97% of physicians polled indicated a preference for telling a cancer patient his diagnosis.8 Of note, however, is a report published in 2001 that found that only 37% of oncologists would give a frank estimate of prognosis, even if asked directly by the patient.9

CULTURAL CONSIDERATIONS

As discussed previously in this series, not all cultures have given the principle of patient autonomy the preeminent status that it occupies in American bioethics. Likewise, some other cultures take a different approach to doctor-patient disclosure. In some cultures, it is accepted for family members to assume the “burden” of knowing the medical facts. A study of the attitudes of elderly subjects from different ethnic groups toward disclosure of the diagnosis and prognosis of a terminal illness was carried out in 31 senior citizen centers in Los Angeles County. Only 47% of Korean Americans and 63% of Mexican Americans, compared with 87% of European Americans and 88% of African Americans believed that a patient should be told the diagnosis of metastatic cancer. Only 28% of Korean Americans and 41% of Mexican Americans, compared with 65% of European Americans and 60% of African Americans believed that the patient should make decisions about life-supporting technology. Instead, they believed the family should make such decisions.10 Similarly, in Chinese, Russian, and Georgian cultures, the cultural norm is to withhold a terminal diagnosis from a patient and allow the family to make medical decisions on behalf of the patient.11,12

The clinician faced with a resident and family with different traditions in the area of truth telling is obliged to develop an understanding of these differences and familiarize himself with how the culture in question tends to communicate about medical issues. In a culture where nondisclosure is the rule, the clinician can often seek permission from the resident to defer information giving and decision-making to the family.

Balancing Competing Responsibilities and Patient Preferences

A commitment to always tell all residents “the truth, the whole truth, and nothing but the truth” might be the simplest approach to the matter of truth telling. However, this kind of absolutist approach fails to take into consideration a resident’s individual needs and ignores situations in which the obligation to veracity should give way to other obligations to the resident. As described in the section above, alternatives to full disclosure might be considered when such disclosure would cause harm by violating cultural norms. Under rare circumstances, the clinician himself may decide that full disclosure will likely result in harm to a resident, and that a competing obligation of
nonmaleficence dictates at least temporary nondisclosure. In such situations, the clinician may invoke what has been referred to as “therapeutic privilege.”

Autonomous decision making includes the right to request “not to know.” For various reasons, either cultural or personal, a resident may request that a physician not inform her of medical information such as diagnosis or prognosis. Often accompanying such a request is a request to defer decision making to either a family member or the physician himself. The clinician who receives this “therapeutic waiver” is well advised to try to explore the basis of the resident’s abjuration of her rights before accepting it at face value. Misconceptions such as, “I wouldn’t understand it anyway,” or “What difference does it make?” can often be dispelled with a small amount of education.

CONCLUSION

As Dr. Hooker warns in the quotation at the beginning of this article, deceiving patients can have dire and unforeseen consequences, whether in the long-term care setting, the acute care setting, or the outpatient setting. Such deception can deprive patients of their autonomy and undermines the patient-clinician relationship. However, indiscriminate compliance with Hooker’s dictum of “strict adherence to the truth” may also cause harm. In the end, perhaps the key to success in truth telling lies in first determining what matters to each of our patients. In the acute care setting, where contact with a patient is often limited to a few days, making such a determination can be quite difficult. The long-term care environment provides caregivers the opportunity to form a long-term relationship with a resident and to “go where the resident lives.” Over the course of a nursing home stay, developments both joyous and painful may arise which have significance for a resident, including landmark family events, medical changes, and disturbing occurrences in the world at large, to name a few. Caregivers in the long-term care setting can play a vital role in making the process of truth telling one that is affirmative for both residents and their families.

REFERENCES